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ABSTRACT

A home-based respite care program for children and young adults with severe and multiple disabilities was conceived and developed by a group of parents and community members. A needs assessment revealed the scarcity of respite care in the Cambridge, Massachusetts area. A pilot program was begun to test the model on a limited basis. Evaluation of the pilot program noted the parents' positive and enthusiastic attitudes towards it, especially regarding the competence of the workers and the flexibility of the time arrangements. A distinctive feature of the model is its Board of Directors consisting primarily of parents of disabled children, and rounded out by special needs teachers, professionals and community members. (CL)

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# EXCEPTIONAL CHILDREN AND RESPITE CARE: PARENTS' PERSPECTIVES

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EXCEPTIONAL CHILDREN AND RESPITE CARE: PARENTS' PERSPECTIVES

In July, 1981, Temporary Care Services, Inc. (TCS) quietly began the TCS Pilot Program, an unusual home-based respite care program for children and young adults with severe special needs. TCS Inc., conceived and established by a group of parents and community members, is a parent-oriented and parent-operated organization. Although the initiation of this Pilot Program was not accompanied by any publicity or fanfare, the services provided had a profoundly positive effect on the families involved. The first section of this article traces the development of this parent-oriented organization; the second section presents the results of the parents' evaluation of the Pilot Program.

Respite care, in its most general sense, is a family support service in which trained workers care for a special needs person--adult or child--enabling the parents to perform other essential tasks or to have the opportunity for some free time. These are options which are rare for those with the sometimes arduous task of raising and caring for those with handicapping conditions.

PROGRAM DEVELOPMENT: A Parent/Professional Partnership

In 1977, a special needs teacher in the Cambridge Public School System became concerned when she and the parents of multiply-handicapped children were consistently unable to obtain any regular relief from their daily parenting resonsibilities. As a result of this teacher's momentum, she, along with parents and service providers in the Cambridge/Somerville area

met to discuss and determine the need for respite care. This small group eventually formed the Respite Care Committee, a volunteer sub-committee of the Cambridge Council for Children, the local branch of the state-wide Office for Children.

After several months' investigation, the Committee determined that, in practice, very little respite care was offered in the area. Although a few agencies did operate some general supportive services for families with special needs youngsters, these services were very limited. Limiting factors included: age of the children, their handicapping condition(s), parental ability to pay, location of the service offered, the time of day they were offered, funding and staffing at the agency. Those youngsters who were most severely handicapped, most difficult to control, and those who are young adults were the least served by existing programs. The Committee concluded that too many special needs youngsters and their families "fell through the gaps" between these agencies, and were not receiving any respite care at all. This gap in service is particularly important when one considers the current state mandate to deinstitutionalize; many families with special needs members at home have few or no supportive services to help them provide a healthful, stable environment.

The Committee, with the cooperation of the Cambridge and Somerville school systems and human service agencies, surveyed two hundred families with special needs youngsters under the age of 22. The results of this survey indicated a need for flexible, quality respite care program in the area, especially for families with teenagers or children with serious special needs.

In addition to this survey, the Respite Care Committee sponsored a Public Forum in an effort to exchange and share information about different types of respite care programs available in other cities and towns. This well-attended forum demonstrated that both interest and need existed in the area. Indicating their interest and willingness to join the Committee, many parents at this meeting--in a true "Catch-22" dilemma--stated that without respite care, they were generally not able to leave their homes to attend meetings.

In February, 1980, spurred on by the interest and need, several Respite Care Committee members, joined by several parents of special needs children and other community members, formed Temporary Care Services, Inc., (TCS), a non-profit corporation. The goal of TCS was then and is now to provide home-based and summer care to those families with special needs youngsters who are not served by other agencies or able to be handled by babysitters: teenagers with severe special needs; multiply-handicapped children; severely retarded; or children who have other serious problems.

A Distinctive Feature: The TCS Board of Directors. TCS is distinctive for several reasons, one of which is its Board of Directors. It is composed primarily of parents of special needs children and rounded out with special needs teachers, professionals, and community members. Since parents have the primary responsibility for the care or a youngster with special needs, TCS considers them to be "experts" in this area. The benefit of the parents' collective experiences on the Board enables TCS to develop and maintain a respite program truly responsive to parents' needs.

This Board of Directors, rather than functioning in a merely advisory capacity, essentially runs the program. In addition a subcommittee of the Board, with the Program Director, wrote a training manual. This Training Manual is based on parents' experiences caring for and coping with their special needs youngsters. The involvement of parents has contributed to maintaining TCS as a parent-oriented agency.

The Pilot Program: A Model for Others. The goal of the Pilot Program, begun in summer, 1981, was to test the home-based model on a limited basis. Ten families received up to 20 hours of respite care a month for three months.

To supervise the Pilot Program operations, a half-time Program Director was hired. The Program Director, a parent herself, supervised the workers, screened families, and worked closely with the Board on personnel and policy matters.

## PILOT PROGRAM EVALUATION

For several important reasons, each parent who participated in the Pilot Program was asked to evaluate it.

First, TCS, Inc., as mentioned earlier, was established as a parent-oriented program. However, being involved in the details of administering a program can sometimes cause one to lose sight of the original intent. The Board was determined not to do this. Secondly, soliciting parents' evaluations would determine whether the Pilot Program had in fact met their needs. After years of receiving various services, the parents in the Pilot Program were extremely well qualified to distinguish a good program from a bad one. Third, the parents' criticisms were critical to the

development of TCS's planned expanded program. Finally, since the Pilot Program was established as a parent-centered program, the Board considered the parents' evaluations to be the best method for determining if the program had reached its objective.

A set of open-ended questions was asked of each set of parents. Their answers to those questions, plus additional comments and thoughts, were tape recorded and later analyzed.

The Pilot Program parents were extremely positive and enthusiastic about the respite care service; its flexibility and the quality of the workers were praised often by all. These parents agreed that respite care meant more to them than simply babysitting, but at the same time, they did not want to see respite care become an intensive educational or remedial program. They did not want a worker doing her homework while their handicapped child was left alone. They wanted interaction, and that was what they got from the TCS program.

> "My daughter is not demanding. She could lay there for days. I need to know that the worker is not sitting there reading a book."

Another parent added in agreement:

> "My baby, when she goes to bed, I want someone to be close to her. This is very important."

It was important to all of these parents that the worker be somebody who could play with the child. Since some of the families served had children who couldn't walk or talk, it was important to them that the worker recognize their child's ability to play and enjoy herself, even if it meant simply tickling or talking to the child. In short, the parents wanted and appreciated the fact that TCS workers treated their children as individuals, and paid close attention to them.

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One parent described an incident in which she felt the TCS worker paid close attention to details and demonstrated concern for both parent and child.

> "The first day that we had a respite worker, my daughter came home from school with a bite mark on her calf. She does not cry.... What was wonderful was this worker was really concerned about it. She called the Program Director. The minute I walked in she told me about it, every detail."

Clearly, this parent was satisfied that the worker was involved in the care of her child in a very personal way.

Several parents added their opinions of what they thought distinguished the high quality of the TCS workers from others they had had in the past.

> "I don't think too much about whether they are professionals. I look to whether they love children."

> "What I like(d) is that not only do they know a lot about special needs but they know that they don't know a lot about special needs. That is even more important."

Several parents compared their TCS workers with other workers who have come into their homes: nurses, physical therapists, teachers, etc. These other workers often assumed the role of expert and without any experience with this particular child's unique needs, immediately told the parents how to take care of their child. These other workers never bothered to ask the parents questions about the child, in spite of the fact that the parents had cared for their handicapped child for years.

> "We have so many visiting nurses come to our house...they don't treat my daughter as an individual, but talk about her in terms of 'they.' A real professional comes to the house, knowing they know very little."

> "People who have the training know a lot of things that others don't. That is nothing compared to the insensitivity (that professionals often show)."

"From the very first time the (TCS) worker touched her, they were very attuned.... They were thinking about how to handle her..."

The parents agreed that highly educated, professional people do not always make the best workers. Sensitivity, responsibility, enthusiasm, and genuine caring were criteria that they valued. They found these in the TCS workers. Coming to the house well-prepared and attentiveness to the children were characteristics highly praised. The parents agreed that the TCS workers were a "double bonus"--highly trained and sensitive also.

One of the evaluation questions was what parents worried about after they left the house, with their child in the hands of the respite worker. Most of the parents worried about what they did or did not tell the worker.

"When I feel most worried is after that first initial meeting. I feel that it is my responsibility to tell this person everything about my child and I feel like I need a whole day."

"(I worry) What did we leave out?"

"I think we worried more before we left, and after we went out we relaxed a little bit more."

In the Pilot Program, each worker carried with them a notebook containing information about the child which the parents and agency had agreed upon. After the first respite visit, the parents felt more comfortable with this system, knowing they could add to it what they wanted. This notebook system helped to relieve some of the fears of forgetting to tell the worker anything--much of it was in the notebook after the very first meeting. Parents heartily approved of the notebook system.

When asked how TCS was different from other programs, the unanimous answer was <u>time</u>. Parents could arrange their own hours with the workers, and workers were available to them at times other than the traditional

working day.

> "(What) was really significant was that we picked the time. I had respite before where it was just what the agency could offer, like, 'oh well, the home health aides only work from nine to five.'"
>
> "The way this was handled was that we got to pick the time. Sure, you had to negotiate a little because the workers have lives, too, but everything seemed to fall into place."
>
> "I like the flexibility of when I wanted to go out."

Another item which compared favorably with other programs is that TCS matched one worker with one family, as the primary worker. An alternative worker was also assigned to the family in case the primary one was not available. This procedure was highly valued by the parents. It personalized the care their child received.

> "I felt that my worker was truly interested in my child. He wasn't just coming for the money or whatever."

The ways that parents used their time varied tremendously. This variety underscores the need for a family-based program in which decisions about hours are made jointly by parents and workers together. One family experienced an emergency when their babysitter suddenly quit. One family used the time to take a weekend away from their teenage severely handicapped children. Another family took their children and the worker on a summer outing together, an event which the family could not have attended together without additional trained help. Still another parent used the time to prepare, without constant interruptions, her child's clothing for camp, while other parents went out to eat, to shop, to spend time with a non-handicapped child in the family, to attend meetings. In other words, this respite time afforded them the opportunity to do those things which many people take for granted. Sometimes this afforded the time for two parents to be alone together; in another situation, it

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allowed a single parent some vital time with other adults. Those of us without special needs children do not truly know what it's like. We can't. The awesome responsibility for life-long care does not have meaning for us, unless we have a special needs child.

> "...When you look at the needs that we have as parents of special needs kids, a lot of time we are right at the threshold. We can deal with it up to here, and then...you just can't deal with it.... Sometimes you don't even realize that you are working at that level (all the time) but you are...."

The importance of TCS to the parents is that they were able to use their respite time in ways that they determined were needed, when they needed it the most. This is and should remain the true meaning of respite.

SUMMARY. The difficulties experienced by parents of special needs children are as varied and as enormous as the joys and hopes they feel. The TCS, Inc. Pilot Program and this article demonstrate quite clearly that a flexible, parent-oriented program can provide much needed support and relief for parents. The issue which the human services agencies must define is not what really is a "problem" for a family or what acceptable level of "problem" must exist before help is dispatched; the issue to be defined is what works best for parents and agency combined. As the TCS Pilot Program parents made abundantly clear, it is possible to provide some relief from the everyday chores and tasks parents of special needs children must face--often for years. For those parents who have decided to keep their special needs child(ren) at home, despite enormous personal and familial costs, respite is a vital support component, as this evaluation indicates. As one parent expressed it so well:

"At night, I find that the day has gone by and I have not had much time to myself. Although many mothers of small children have little free time, for most of them the condition is only temporary. Their children grow up, and gain more independence with each passing day. In my case, I have been doing this type of care for 20 years and look forward to a lifetime of the same activity.... We are satisfied that the choice we made to care for our children at home is the right one for us. I hope we will never be denied that choice."

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